

CONSUMER INFORMATION, COMMUNICATION & INVOLVEMENT

FINDINGS AND RECOMMENDATIONS

I. INTRODUCTION

Rapid changes in the health care delivery system have resulted in elevation of the importance of consumer information and involvement. The potential benefits of managed care, namely lower costs, higher quality of care and greater consumer satisfaction will be realized only in a system characterized by active and meaningful consumer participation.

This paper addresses the interrelated issues of consumer information and involvement in the health care system. A brief section on communication of consumer information is also included to highlight the importance of the format in which information is made available or presented to consumers. The paper is structured in two parts: the first will present background, principles and recommendations for improving managed care through better and more accessible consumer information, and the second will do the same for effective consumer involvement.

II. CONSUMER INFORMATION

The historical physician-patient relationship, which was characterized by the professional authority of the physician and a relationship based upon trust, has been altered by the introduction of managed care. According to Bradford Gray of Yale University, this relationship has also been “strained in recent decades by exploding health care costs, accompanied by much publicity about malpractice crises, fraud and abuse, inexplicable variations in patterns of care and high levels of inappropriate services.”¹ Gray also notes that managed care has added sources of doubt in the trustworthiness of physicians by introducing compensation arrangements that may create conflicts of interest, introducing external parties into the physician-patient relationship and implementing rules that limit the alternatives that doctors can offer patients.² (See the Task Force paper on the Physician-Patient Relationship.) In an environment in which a third party can intervene, the patient needs access to and an explanation of information relevant to the decision about appropriate treatment. In addition, with the health care delivery system’s shift from a focus on treatment to prevention, consumers need knowledge about health promotion activities in general and about their own health status. These shifts imply a need for health care information, communicated in an effective manner.

In managed care, the consumer becomes an advocate for him or herself and a “partner” in his/her care. In this new role, the consumer needs access to a range of information on plans and providers. While a great deal of information is provided to consumers by health plans and/or submitted by health plans to regulatory authorities, the extent to which consumers are able to use this information to compare plans and make effective decisions is unclear.

¹ Gray, B, “Trust and Trustworthiness in the Managed Care Era” *Health Affairs* 16:1, January/February 1997, 34-49.

² Ibid.

In addition, much information that consumers need to participate effectively in their health care remains unavailable to them.

California consumers have long voiced concerns about the availability of information on managed care organizations collected and disseminated by state oversight agencies. In a 1992 study, the California Auditor General found that the DOC had been lax about maintaining its public access files, responding to complaints and performing required monitoring visits.³ In a 1996 report, Consumers Union documented the difficulties consumers have in obtaining information from the Department of Corporations.⁴ This report noted that although the Knox-Keene Act requires the DOC to educate and inform consumers about HMOs,⁵ DOC provides consumers with little information to assist them in choosing or using health plans.

Consumer advocacy groups and private organizations use a combination of government-generated and market-generated information to provide consumers with health care system information and various types of “rankings,” generally at the health plan level. A broad range of resources have also been developed to educate consumers on clinical issues and help them respond to their role in the managed care system. A great deal of information that was until recently considered “professional” has been brought into the public domain. Resources designed to help consumers access information and educate themselves about a broad range of clinical issues are provided in print and via media such as videotapes and Internet sites. Examples of these initiatives range from “ask the doctor” email forums to consumer-focused clinical education and decision-making tools to patient advice/peer groups for people with specific conditions and diseases.

A. Communication of Consumer Information

While plans, providers and independent monitoring organizations currently collect a great deal of data on performance of health care organizations, this information is often not translated into measures that are useful to consumers. In addition, lack of standardization of information collection and dissemination has made it difficult for purchasers, plans and advocacy groups to provide consumers with useful, relevant information for plan and provider selection.

Recent studies reveal significant problems in communication of basic managed care information to consumers. The vast majority of consumers do not currently understand even the fundamental operations of the plan in which they are enrolled (e.g. how managed care plans differ from traditional, unmanaged fee-for-service indemnity insurance).⁶ In addition, a recent study of the “readability” of health insurance literature and contracts found that the average document was written at a reading level of third/fourth year college

³ Report by the Auditor General of California, *The Department of Corporations Can Improve Management of Medical Surveys and Consumer Complaints in its Health Care Service Plan Division*, P-15, May 1992.

⁴ Hamburger E, “A Shot in the Dark: The Department of Corporations Fails in its Job to Educate and Inform Consumers about Choosing an HMO,” Consumers Union of the US, Inc., West Coast Regional Office, April, 1996.

⁵ California Health and Safety Code 1342(b) (West 1996).

⁶ Isaacs, SL, “Consumers’ Information Needs: Results of a National Survey,” *Health Affairs*, Winter 1996.

to first/second year graduate school⁷. In contrast, the results of the 1992 Adult Literacy Survey conducted by the US Department of Education indicated that writing directed at the “general public” should be at the seventh or eighth grade level⁸.

Communication of plan features and requirements in terms and language accessible to enrolled consumers will enhance both efficiency of operations and consumer satisfaction with managed care plans. Employer coalitions, such as the Pacific Business Group on Health (PBGH), have made the most extensive and successful efforts at providing such information to date.

B. Principles for Consumer Information

The following principles should guide development of recommendations regarding consumer information in health care:

1. Full and accurate disclosure of appropriate information can serve to foster best practices.
2. Consumers’ ability to understand differences in quality among health plans and providers is critically important to efficient functioning of the health care delivery system.
3. Consumers’ ability to choose among and effectively use health plans and providers is critically important to efficient functioning of the health care delivery system.
4. Consumers should have unbiased, standardized information about health plans, medical groups and physicians.
5. Dissemination of accurate, useful information will enhance consumer trust in the managed care system and drive quality improvement by plans and providers.

C. Recommendations for Consumer Information

1. The state agency(ies) charged with oversight of managed care (currently the DOC and DOI) should issue a request for proposals for annual production of a consumer-focused, educational booklet on the health care system in California.

This publication should be produced by an organization with experience in health benefits purchasing and communication. It should be produced at a simple enough reading level and in sufficient formats and languages so that it is useful to the great majority of consumers. The publication should be tested and evaluated with consumers to determine that it is understood by and useful to consumers. When data support that the publication is useful and understood, a dissemination plan should be developed to ensure that it is distributed to all managed care consumers in as cost effective a manner as possible (e.g. mailed with plans’ enrollment materials, made available at providers’ offices and hospitals and posted on the Internet). Organizations might also consider including dissemination of these materials as part of their “community benefits” programs.

⁷ Hochhauser M, letter to the Editor *Health Affairs* September/October 1997, p 220.

⁸ Kirsch IS et al., “Adult Literacy in America, A First Look at the Results of the National Adult Literacy Survey,” Washington, US Department of Education, 1993.

2. In addition to the recommendation in the Task Force paper on Standardizing Health Insurance Contracts that the state agency charged with oversight of managed care (currently the DOC) convene a working group to develop a standard outline and definitions of terminology for the Evidence of Coverage (EOC) and other plan documents, we recommend that the above mentioned agency:

Create and update at least annually a “standard product description” in a format to facilitate direct comparison of plans by consumers, designed with input from stakeholders, in as non-political a process as possible. The CalPERS format could be considered as a model for this document. The DOC should require plans to use the standard format to present information about any product they offer.

This standard benefit characteristics document should include a statement on how drug formulary decisions are made; should describe key elements of the plan’s grievance procedure (including a description of any arbitration processes); should include independent (i.e. not self-reported) “exit polling” information on number disenrolling and primary reasons for disenrollment, when available; and should offer, for each plan or medical group with which the plan contracts, a brief but specific description of the referral and authorization process, and the process through which medical decisions are made. The DOC should make these descriptions available to consumers at a nominal charge and should make this information available on the Internet.

3. Plans should be required to submit to the agency charged with oversight of managed care information on approximately 10 major health conditions or illnesses requiring referrals to specialty centers (e.g. bone marrow transplants, coronary artery bypass grafts). Data should be reported on an annual basis for the prior year, and should include, for each condition or procedure: where and from which physician(s) the patient received care; how many of the procedure in question the center to which the patient was sent performed in that year; and, when risk-adjusted outcomes become available, outcomes measures. Data should be presented at the plan level, and where appropriate at the medical group or IPA level. Provisions should be made to ensure that data is presented in such a way that patient confidentiality is maintained. This information should be made available to consumers and organizations upon request.
4. Upon request by an enrollee or a member of the public, all plans and medical groups should be required to make available at a nominal charge copies of any written treatment guidelines or authorization criteria for a given condition.
5. The agency(ies) charged with oversight of managed care (currently DOC and DOI) should cause to be created a “Super Directory” of physicians and other primary care providers (e.g. advanced practice nurses), hospitals, clinics and medical groups participating in health plans, indicating which plans or groups they contract with. The purpose of this directory is to ensure that consumers receive accurate information on whether a particular provider or group will be available to him/her as a member of the plan. Primary care providers’ entries should indicate which medical groups or IPAs they belong to, whether or not they are accepting new patients and to what facilities or specialists their patients may be referred. This information should be made available

to all consumers at the time of enrollment and renewal and to individual consumers at any time upon request.

Plans should be required to update the information for their participating providers on the Internet continuously, and to update and make it available in print at specified locations at least quarterly. This information could then be made available to consumers through employee benefits offices, libraries and consumer advocacy and assistance organizations. Plans should be required, upon member or potential enrollee request by telephone to provide “Super Directory” information for their participating physicians/providers, e.g. to indicate whether a particular provider or provider group is a member of the plan’s network, to indicate whether a participating primary care provider is accepting new patients or to provide a list of plan-approved specialists of a certain type in a certain geographic area.

Every effort should be made to minimize additional paper flow: paper copies of the Super Directory should be made available at a limited number of public sites, and an emphasis should be placed on development of electronic technologies for updating and providing information (e.g. automated telephone systems, Internet).

6. (a) The state agency charged with oversight of managed care organizations’ (currently DOC’s) report on grievances should be expanded to include more detailed and meaningful information on grievances. The DOC currently provides information on complaints (in DOC terminology “requests for assistance” or RFAs) filed with the Department in writing, after the plan has had 60 days to resolve the problem. Current information provided by DOC includes a report on the number of complaints by type of complaint and plan.

The Task Force recommends that the report be expanded to include an indication of the severity and urgency (as defined by threat to life and health) of the complaint and whether and what action was taken by the plan and/or DOC in response to the complaint. This additional information is critical if consumers are to be able to use the complaint information in choosing a plan. This recommendation would provide an improvement in disclosure to consumers using information that is already available to DOC. Because measures of grievance severity/urgency may not have been developed by regulatory agencies or plans to date, the Task Force recommends that a collaborative effort to develop such measures be undertaken.

(b) See the Task Force paper on Dispute Resolution for additional recommendations on reporting and disclosure of grievance information, including a recommendation which provides for expansion and publication of public reports on complaints and grievances filed with health plans.

7. The state agency charged with oversight of managed care should encourage and support, to the extent possible in collaboration with private sector efforts, gathering of additional standardized patient satisfaction and quality data at the provider group level (for groups and IPAs exceeding a certain size threshold) as well as the plan level. This effort should not duplicate current initiatives, but should include plans and groups who have not been included in surveys and reporting efforts to date and should expand on

measures currently being collected. The PBGH/Medical Quality Commission “Physician Value Check” could be considered as a model for medical groups, and the FACCT⁹ framework is one example of a model for collection of data at the plan level.

8. The Task Force recommends that employers who pay a portion of employees’ health benefits coverage begin to increase awareness that dollars spent on health benefits are a part of employees’ total compensation by including such payments as a separate line item on employee pay stubs. Employers may choose appropriate alternatives -- such as reporting on total compensation and/or health insurance premiums for each employee -- which achieve the goal of increasing employee awareness of the cost and value of health benefits. Employers should be encouraged to collect information from their employees on their experiences and problems with health plans and medical groups so that this information can be used in the plan negotiation process.

Please note that The Task Force paper on Provider Financial Incentives presents several specific recommendations regarding disclosure of information about financial arrangements and payment mechanisms to consumers.

III. CONSUMER INVOLVEMENT

Formal consumer involvement mechanisms are necessary to ensure that consumers have a “voice” in shaping the health delivery system and their role in it. While most health plans have some member involvement mechanisms in place, few have implemented extensive programs for consumer feedback that have proven effective. Most consumer activity has focused on issues such as review of marketing materials and grievance procedure policy development. Most plans acknowledge that while they attempt to obtain member input on print materials, they do very little formal testing of educational and marketing materials to determine whether consumers understand or can effectively use them.

Ombuds programs, member advisory committees and tools such as the “Consumer Feedback Loop”¹⁰ have been developed to allow all parties in the system to obtain and benefit from the input of members. (An example of information gathered in a representative Consumer Feedback Loop is included as an attachment to the background paper for this report.) While purchasers, plans, providers and consumers have all recognized the benefits of such involvement mechanisms, because the spirit of the Knox-

⁹ The Foundation for Accountability (FACCT) is a not-for-profit coalition dedicated to helping consumers make better health care decisions. FACCT has released measures that attempt to create a relevant, comprehensive picture of quality of care for *specific conditions*—like asthma or diabetes, *lifestages*—like pediatrics or end of life, and *population status*—like health status over 65 or health risk behaviors. FACCT creates comparative information by organizing and weighting data from HEDIS, FACCT measurement sets, the Agency for Health Care Policy and Research’s CAHPS, the Joint Commission on Accreditation of Health Care Organizations’ ORYX and public health databases.

¹⁰ The Consumer Feedback Loop, a tool developed by California Health Decisions, is a model for improving health care quality that involves patients, providers, purchasers and health plans in a consumer-driven process of research, solutions, change and evaluation. The Consumer Feedback Loop is a process that fosters cooperative efforts towards quality improvement. Its goal is to shape change in a health care delivery system or structure around the best interests of the consumer.

Keene provisions for consumer information and involvement are not being achieved, strong incentives will likely be necessary if plans and providers are to seek active participation of members in formulation of policies, marketing materials, product design and plan operations and evaluation.

Attempts to improve upon the current level and nature of consumer information and involvement should be driven by an understanding of consumer values. Advocates and studies have characterized seven consumer values that relate to the health care delivery system¹¹:

Affordability: Quality health care at a reasonable price. Members most often cite affordability as their primary purchasing criterion and express a fear of losing access to quality care because costs are too high for their employers or themselves.

Choice: Consumers are allowed to choose their health care providers, ideally at each of three levels: the plan, the medical group and the physician. Consumers often feel that they do not have the information they need to make informed choices.

Accountability: Consumers enrolled in a plan are presented with clearly identified agents and processes through which to resolve problems. Members are concerned that accountable organization resolves problems in a pre-stated and timely manner.

Personal Responsibility: The managed care operating environment expects consumers to become “partners” in health care. Member involvement includes two discrete dimensions: a greater level of self-care, behavior modification and preventive activities and member responsibility for some of the “navigation” and coordination of their health services.

Fairness: Members feel that all patients are treated with the same care and that medical decisions are just. Members generally talk about fairness on a global level; they not only seek fairness for themselves and their families, but feel that there should be at least a minimum threshold of care available to all people.

Dignity/Respect: Physicians and health plans treat patients as capable and explain conditions, treatment options and patient responsibility clearly.

Quality: Consumers understand and have relatively easy access to services and obtain good medical outcomes given their condition.

A. Principles for Consumer Involvement

The following guiding principles serve as the basis for recommendations as to how increased consumer involvement can improve the managed care system.

1. Member/patient involvement in managed care decision making, including member participation in product design, development of marketing materials and quality improvement processes will improve managed care quality and enhance consumer service and satisfaction.

¹¹ These values have been developed by California Health Decisions, and are described in more detail in its “Condition Critical Project” report.

2. Member/patient involvement mechanisms (such as Consumer Feedback Loops, ombuds programs, member advisory committees and member participation in policy and committee structures) should be created and employed to improve the overall efficiency of plans and medical groups.
3. Strong public and private incentives, in addition to the market-driven need to attract and retain customers are necessary to ensure that health plans and provider groups develop organized systems of consumer involvement and advocacy.

B. Recommendations for Consumer Involvement

1. (a) Health plans will enhance consumer trust by formally including consumer input into policies and practices across all levels of the plan. The Task Force strongly encourages health plans and consumer groups to work together to design workable mechanisms for doing so. State government should exercise its considerable bargaining power as a health care purchaser by ensuring that members' interests are incorporated into health plan design and operations.

(b) In addition, we recommend that Knox-Keene be amended to include more extensive provisions for consumer involvement in plans' governance, policy making and operational structures. Several features of the health care market render health plans more deserving of state-mandated forms of governance than organizations that produce or provide other goods and services:

- Health care is more personal in nature than other goods and services; decisions about health care and treatment can involve significant bodily harm and/or be life threatening. Consumer expectations for regulation in health care are higher than they are for most other goods and services.
- Consumers have a compelling interest in provision for and protection of public health.
- Consumers are "obligatory users" of the health care system (i.e. many sick and/or pregnant consumers must use the system whether they want to or not).
- Health care is characterized by imbalances in availability of information to consumers more significant than that in most other industries.

Under Knox-Keene, HMOs are currently required to:

- Establish a governing body which is composed of at least one third subscribers or enrollees
- Establish a standing committee which is responsible for public policy participation and whose recommendations and reports are regularly and timely reported to the board. The membership of the committee shall be at least 51% subscribers/enrollees,
- Describe the mechanism by which enrollees/subscribers can express their views on public policy matters, and

- Establish procedures to permit subscribers and enrollees to participate in establishing the public policy of the plan and incorporate these procedures into the plan's bylaws.

The proposed revision of Knox-Keene would read as follows:

[Note to Task Force members: After discussion of this recommendation at the 11/25 meeting, ERG members determined that the spirit of the recommendation would be best maintained by connecting bullets 1 and 2 below with “or” instead of “and” rather than substantially altering the text or substantive content of the recommendation. Thus the language proposed for Task Force adoption will be different from that on which “straw polls” were taken at the 11/25 meeting. This change meets the concerns of the Chairman and several other Task Force members regarding potential conflict of interest with the fiduciary responsibilities of board members.]

- Establish a governing body which is composed of at least one third members or enrollees and ensure that sufficient resources are made available to educate enrollee board members so that they can participate effectively. Enrollee board members should neither be employees of nor have a significant financial interest in the organization or competitor organization, *or*
 - Establish a member advisory committee to ensure that members' values and needs are integrated into the design, implementation, operations and evaluation of the plan/HMO. This committee shall communicate and advocate for members' needs and serve as a resource for the governing body and HMO/plan administrators. It shall be responsible for establishing mechanisms and procedures for enrollees to express their views and concerns about the HMO/plan. The plan attributes/functions this committee may address include but are not limited to: benefits and coverage, member communications, quality assurance, marketing and grievance resolution, *and*
 - Upon request by the state agency(ies) responsible for regulating managed care, accrediting organizations or other interested parties, (a) describe the mechanisms and lines of accountability used for obtaining and incorporating member feedback into policies and practices across all member-related departments/divisions, *and*
(b) demonstrate how member feedback has been incorporated into plan policy, operations and evaluation.
2. The Task Force recommends that purchasers and employer groups, including government agencies, contracting for health care should exercise their bargaining power to encourage plans to ensure that medical and other provider groups develop and utilize mechanisms of consumer feedback.
 3. The Task Force recommends that accrediting bodies develop standards regarding plans' and provider groups' utilization of validated, reasonable consumer feedback in policy development and implementation.

Revised Draft – For Discussion and Adoption

(Contents and recommendations herein have not been approved by the Task Force)

4. The Task Force encourages collaborative efforts among government, foundations, plans, provider groups and purchasers to fund expansion of organized systems of consumer involvement.
5. The Task Force recommends that the appropriate managed care oversight agencies (currently DOC, DOI and DHS) have member advisory committees responsible for ensuring that managed care plan members' values and needs are integrated into the collection of information from and regulation of managed care organizations.